

**Children's Special Health Services
Family Advisory Council Meeting Minutes
May 21, 2005**

Present from the Family Advisory Council: Donene Feist, Jennifer Restemayer, Lisa Beckman, Lori Hanson, Carla Peltier, Karen Watt, and Evelyn Klimpel.

Present from CSHS: Terry Bohn, Leann Bayman, Sue Burns, Kora Dockter, and Tammy Gallup-Millner.

Present from the Medical Service Division: Dave Zentner.

CSHS Medical Advisory Council Meeting:

Tammy briefly reviewed some of the highlights from the Medical Advisory Council meeting and relayed that Family Advisory Council members would receive a copy of the minutes when they became available.

Family Advisory Council Updates:

Terry provided an updated membership list, which included Karen Watt as our newest member. Bylaws dated May 2004 were reviewed with no changes recommended for the current year. The Review/Recommendation Form was addressed and will be updated for the next meeting.

CSHS Program Updates:

Reports from CSHS program areas:

- Terry relayed he will be resigning from CSHS effective 5/27/2005. Staff and council members acknowledged his many years of leadership of the council.
- With the passage of SB 2163, Kora has led workgroup activities to support web-based training of providers to assure students can self-administer emergency medications in school. She also relayed that a pilot for cystic fibrosis screening will be initiated this summer as part of the metabolic screening program.
- Sue relayed clinics are wrapping up for the school year and that we have been informed that Dr. Haasbeek, a pediatric orthopedist, will be returning this fall to MeritCare but will not be doing any outreach services. First Sounds, ND's early hearing detection and intervention program, received another three-year grant. CSHS also helped with a physician survey for NCHAM.

Legislative and budget updates:

- Dave and Tammy provided the following updates:
 - Appropriations for Medicaid allow for maintenance without any new initiatives.
 - The CSHS budget was funded as initially approved in the Governor's budget.
 - HB 1148 makes the personal care option permanent.
 - HB 1459 allows for disease management programs, which will likely focus on expensive cases and some disease states.

- HB 1470 pertains to the Drug Review Board. There will be no prior authorization for drugs to treat mental illness.
- SB 2395 created a program for children with Russell-Silver Syndrome and also addresses a small Medicaid waiver and a child health study.
- Tammy relayed that once legislative direction is established with HCR 3054, one of the chosen interim studies, the Medical Needs Task Force will begin to meet again.
- MMIS – a new computer system was funded. Donene relayed she hoped that the new system would be able to identify CSHCN's.

Other:

- Champions for Progress is an initiative funded by MCHB to improve the system of care for CSHCN and their families. A small grant was recently applied for with the help of Family Voices and the Family-to-Family Support Network to support activities around medical home and transition. A national meeting will be held this fall and a ND team will attend to support additional systems related planning.
- Terry relayed that the Pregnancy Risk Assessment Monitoring System (PRAMS) report is available online at <http://www.ndsu.edu/sdc/data/ndprams/htm> if anyone is interested in the publication.

Announcements:

- Applications for CSHS grant funds were mailed out on April 19, 2004 with a proposal due date of May 20, 2005. This process is used to determine funded services during the biennium.
- The ND OneStop Project held focus groups in March for families who had children with intellectual disabilities and mental illness.
- Family Advisory Council members were encouraged to attend the 2005 ND Family Connections Spring Conference: When Children Have Special Needs June 8-10, 2005 in Fargo. A pre-conference will be held June 7th. Family stipends may be available by calling Andre at the North Dakota Center for Persons with Disabilities at 1-800-233-1737. CSHS staff and possibly Dave Zenter will participate on the Panel and Round Table discussion group. Council members suggested covering information from the legislative session and access to care issues.
- Terry relayed that CSHS needs assessment documents that have been worked on over the last year are now on the web. Topic related fact sheets are forthcoming.
- Information has been submitted to the federal government on “rehab services” covered under Medical Assistance. Coverage for case management has been an issue. A commission to look at Medicaid reform will be established and a site visit by the CMS Director is planned for June 2005.

Input Requested:

Input was request for the following:

- County social service/public health care coordination training agenda: Council members were advised the two-day training would be held in October in conjunction with Health Tracks. Ideas for the training included:

- Community resources (e.g.) support groups, Family-to-Family, and Family Voices – some people may be afraid to refer to family organizations as it can be kind be turf.
- Advertise children's services; encourage people who determine eligibility to solicit more information.
- Provider screening – let families know information; don't screen information for families; let them decide.
- Not everybody walks through the county door; other providers may not pass on information due to time constraints; other approaches are needed (e.g.) posters.
- Encourage social workers to assess family needs; families will let them know if they feel things are too intrusive.
- Tammy relayed that eligibility and care coordination forms were being revised and made into e-forms. Input on care coordination service plans was solicited with the following comments:
 - Members like the medical home/PCP on the forms.
 - Resource list:
 - Resource list was good even though it was long.
 - It is important that family organizations are included on the resource list.
 - Clarify whether families are given a brochure or whether someone will actually make the connection for them after an authorization to disclose has been obtained. Some families want social workers to know if the resource is a good fit. Other families want all the options and will screen information themselves.
 - Expand Developmental Disabilities to include Infant Development/Early Intervention
 - Add independent living centers to the list.
 - Service plan forms:
 - There are a lot of places to go back and look for interventions on the long form. These should be moved to one area so the plan is on one page.
 - Consider adding a check box for not applicable.
 - The trigger questions help stimulate thinking for the assessment.
 - Consider adding a question “ where do you think you struggle the most”.
 - Provide a copy of the form to families.
 - Keep quarterly contacts as part of the service plan.
 - Combine the two forms; the short form won't stimulate as much dialogue but it won't overwhelm families either.

CSHS Annual Plan for the MCH Block Grant:

The draft plan for the period 10/2005 – 9/2006 was reviewed. The following comments were received on each performance measure:

- FPM #1 screening – Is childbearing age correct?
- FPM #2 family partners in decision-making and service satisfaction -

- FPM #3 medical home – Is there a goal for the percent with a service plan?
- FPM #4 insurance – Correct typo; change will to with
- FPM #5 service system organization –
- FPM #6 transition – Keep age 14-21.
- FPM #12 hearing screening – What does stakeholders mean?
- SPM #8 extraordinary medical needs – Are families are part of this effort?
- SPM #9 specialist doctor – Minnesota has a new policy regarding level 2 care to major referral centers.
- SPM #10 public information services plan –

Family Participation Ranking:

Council members were asked to rate six characteristics measuring the degree of family participation in the CSHS program. Results from the Family Advisory Council and CSHS staff ranking will be compiled for the application that will be submitted July 15, 2005.

Next Meeting:

The next meeting will be held Saturday, August 20, 2005 from 9:00 – 12:00.